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A focused ethnographic study

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Support groups for carers of a person with dementia who lives at home: A focused ethnographic study

Running title

Support groups: a focused ethnographic study

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Author contributions

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Criteria	Author Initials
Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data;	JL, MB, EES
Involved in drafting the manuscript or revising it critically for important intellectual content;	JL, MB, EES, PUP
Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content;	JL, MB, EES, PUP
Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.	JL, MB, EES, PUP

ABSTRACT

Aims: To explore and understand carer participation in support groups when caring for a person with dementia who lives at home

Design: Focused ethnographic design.

Methods: Participant observations and semi-structured interviews were conducted from January - December 2015. The data were collected from four support groups in the Danish primary health care system. Interviews were conducted with 25 carers. An inductive content analysis of the data was performed.

Results: Three themes were identified: emotional well-being due to peer and family support, emotional sense of togetherness despite hardships and emotional and ethical considerations in caregiving.

Conclusion: Support group participation with positive peer interaction increases carer self-esteem and feelings of togetherness, as well as an awareness of maintaining the care receiver's dignity and prevention of conflicts with families, resulting in an improvement in carer well-being, leading to increased motivation to continue caring. Carers who hid their group participation face a potential conflict with the care receiver.

Impact:

- By sharing positive experiences, carers have increased self-esteem and feelings of togetherness, which can have a positive impact on their motivation to continue caring.
- Positive peer interaction encouraged a shift in focus from negative to positive experiences, resulting in an improvement in carer well-being.
- Joint group participation prevented conflicts in families.
- To protect the care receivers, carers kept support group participation a secret.
- Health care professionals could improve carer well-being by focusing on positive caring experiences in support groups.

KEY WORDS: dementia, support group, caregiver support, life experiences, nursing, focused ethnography, content analysis, positive experiences

INTRODUCTION

Worldwide, an estimated 50 million people over the age of 60 live with dementia; this number is likely to rise, with approximately 10 million new cases diagnosed every year (World Health Organization, 2017). The progression of dementia leads to cognitive deterioration with changed behavior, loss of memory and loss of the ability to perform basic activities of daily living (World Health Organization, 2012). Studies have shown that most

people with dementia who live in their own homes receive unpaid care from family, friends or neighbors (Egdell, 2012; Golden & Lund, 2009). As the care receiver's cognitive deterioration increases, the demands for care often lead to carers gaining negative life experiences by feeling stressed and burdened (Chu et al., 2011; Keyes et al., 2016). As caregiving becomes more time consuming, the carer's social network shrinks, resulting in isolation and loneliness (Yu, Cheng, & Wang, 2018). Research has shown that support groups where carers share the negative experiences of providing daily dementia care can be an effective way of relieving caregiver stress and burden (Chien et al., 2011; Willis, Semple, & de Waal, 2017). However, only a limited number of studies have shown how the sharing of positive caring experiences in support groups may be a further source of enrichment and stress relief (Lauritzen, Pedersen, Sørensen, & Bjerrum, 2015; Lloyd, Patterson, & Muers, 2016; Shim, Barroso, & Davis, 2012; Yu et al., 2018). Consequently, focusing mainly on negative experiences can limit our comprehension of the experiences shared by carers in support groups. Greater insight can be achieved by including both positive and negative caring experiences to add new balanced dimensions in understanding carers perceptions of support groups when caring for a person with dementia who lives at home.

Background

To comfort and support unpaid carers of people with dementia who live in their own home, support groups are suggested to decrease stress levels by sharing negative experiences (Golden & Lund, 2009; Willis et al., 2017). However, carer participation in support groups has led to mixed findings. Peer interaction in a support group where carers share negative experiences can alleviate feelings of isolation, loneliness, stress, burden, depression and fatigue (Chien et al., 2011; Egdell, 2012; Hornillos & Crespo, 2011; Lauritzen et al., 2015). Conversely, there are conflicting studies on the impact of support group participation for

carers, with little evidence that carer interactions in support groups can alleviate stress and burden or increase carer well-being (Chu et al., 2011; Dam, de Vugt, Klinkenberg, Verhey, & van Boxtel, 2016; Pinquart & Sörensen, 2006). Previous research indicates that the stress and burdens on carers are multidimensional and therefore cannot be fully encompassed by the effect of sharing negative experiences in support groups (Ankri andrieu, Beaufils, Grand, & Henrard, 2005; Dam et al., 2016; Han et al., 2014). Contrastingly, an evaluation of 40 peer support groups concluded that participating in a support group is meaningful for carers, but more knowledge is needed on how to encourage positive interpersonal support (Keyes et al., 2016). By exploring carer interactions in support groups and focusing specifically on shared negative and positive experiences of caring for a person with dementia living at home, we attempt to improve the understanding of this phenomenon. These insights are particularly important because participation in a support group can help carers to overcome daily obstacles as they gain insight into the cultural, social, physical and emotional experiences of caring for a person with dementia (Keyes et al., 2016; Lloyd et al., 2016; Yu et al., 2018). These emotional experiences encompass anger, sadness, stress and frustration as well as love, respect, reciprocity, gratification, enjoyment and satisfaction (Alvira et al., 2015; Chu et al., 2011; Lauritzen et al., 2015; Lloyd et al., 2016; Yu et al., 2018). Previous studies indicate that the coexistence of negative and positive experiences should be considered in caregiver support services, as sharing positive experiences in support groups can build close, positive peer relationships (Lauritzen et al., 2015; Signe & Elmståhl, 2008; Yu et al., 2018). Furthermore, understanding how carers' shared experiences can have an impact on carer well-being and by association the well-being of the care receiver, is important for determining when carers benefit from support groups and what is meaningful about such groups. Therefore, for the carers, positivity might help reduce the negative consequences of providing care.

THE STUDY

Aims

The aim of this study was to explore and understand carers participation in support groups when caring for a person with dementia who lives at home.

Design

Focused ethnography made it possible to explore the complex social interactions that occur between carers in support groups (Cruz & Higginbottom, 2013; Knoblauch, 2005). Focused ethnography was appropriate for exploring support groups as it is characterized by short term filed visits focused on a group of people sharing experiences through interaction and communication (Cruz & Higginbottom, 2013; Knoblauch, 2005). The complex social interaction and cultural context events in support groups were examined through participant observation with a moderate passive observer-as-participant role, field notes and interviews. The moderate passive observer-as-participant role enabled moderate involvement but had a detached role during meetings where the primary author stayed mainly silent unless invited into the group interaction and conversation (Knoblauch, 2005; Spradley, 1980). As an observer, the primary author became a listener in the group conversations and therefore was able to observe the interaction and be a participant as a listener (Wadel, 1991). Focused ethnography enabled an exploration of carer perspectives, values and preferences on subjective experiences while caring for a person with dementia who lives at home (Cruz & Higginbottom, 2013; Higginbottom, Pillay, & Boadu, 2013; Knoblauch, 2005). This approach provides an in-depth understanding of the situated experiences that carers voiced during peer interactions in support groups.

Participants

A total of 25 carers were included in this study (19 women and 6 men). The relationships between the carer and the patient included spouses, two pairs of female siblings, a father/husband and his adult daughter, daughters, a daughter-in-law and a neighbor. The carers' ages ranged from 40 to 82 years old. In conformity with focused ethnography, the key participants were purposefully selected based on their knowledge of and experience in caring for a person with dementia who lives at home. Furthermore, the carer must be participating in a support group (Higginbottom et al., 2013). The key participants contributed to a variation that was unique and rich in information and brought a wide range of perspectives and in-depth nuances to the study. Thus, enabling a representation of the full extent of the explored phenomenon (Hammersley & Atkinson, 2007; Higginbottom et al., 2013). The inclusion criteria were carers aged 18 and older who participated in support groups and cared for a person with dementia who lives at home. The primary author obtained access to the groups through personal and written introduction of the project to the municipality dementia coordinators, who acted as gatekeepers (Hammersley & Atkinson, 2007).

The dementia coordinators recruited and selected carers who wanted to join the municipalities support group program and presented them with a letter inviting them to join the study. The carers were invited to an introductory meeting about the support groups, where the primary author introduced the study orally. All invited carers were included in the study.

Data collection

This study was performed in 2 out of 98 Danish municipalities. The data were collected from four support groups in the Danish primary health care system (two groups each in two Danish municipalities). The dementia coordinators in the selected municipalities were nurses and

other healthcare professionals with an additional 30 ECTS education credits in dementia and had long-term experience working with support groups. In 2018, there were approximately 200 dementia coordinators in Denmark. The coordinators provided dementia care and services between the person living with dementia, carers and the primary and secondary health care system as well as facilitate support groups. Support group participants were identified through self-referral and professional referral (Danish Health Authorities, 2018).

All support group meetings were held in meeting rooms at the two municipalities' Health Care Centers, located in a converted school building and in an annex to a nursing home. The meeting rooms were set up conference-style with a large table. The carers were divided into four support groups with seven, seven, seven and four carers, respectively. The support groups were organized as supportive interventions and were led by dementia coordinators (Sorensen, Pinquart, & Duberstein, 2002). Each group met six to nine times.

Data collection was based on participant observations and semi-structured interviews (Hammersley & Atkinson, 2007; Knoblauch, 2005). Data were collected from January to December 2015 by the primary author. In all four support groups, the carers invited the primary author to sit at the conference table and participate in coffee breaks to build and maintain friendly relationships (Roper & Shapira, 2000; Spradley, 1980). At the meetings, the primary author focused on observations based on an observation guide produced by the research team that included questions such as "How do the carers interact with each other?" (Spradley, 1980). The participant observations moved from general, descriptive, grand-tour observations of what occurred in the social situations in the groups to more specific, focused, selective mini-tour observations in the context of the meetings, where the carers' interactions and dialogue and the primary authors' own reflections were recorded in fieldnotes (Spradley, 1980). The fieldnotes were handwritten during and immediately after participant observations and interviews. After each meeting, the fieldnotes were transcribed into detailed, coherent

descriptions (Emerson, Fretz, & Shaw, 1995). Participant observations were performed during 30 support group meetings, which lasted an average of two hours. The cumulative time in the field was 60 hours. Participant observations were followed up with semi-structured interviews with the carers. A semi-structured interview guide with open-ended, general and individual questions based on the participant observations was used (Spradley, 1979). The interviews took place according to the preferences of those interviewed and were conducted at the two municipality Health Care Centers (n=23) and in the carers' private homes (n=2) and lasted on average 1 hour and 5 minutes. The primary author conducted 25 interviews, which were transcribed verbatim. During the data collection, an initial data analysis as part of the constant reflexivity was performed in a continuously iterative process throughout the fieldwork and interviews (Emerson et al., 1995) to develop follow-up questions and provide guidance for future observations to provide a detailed description of what was observed and conceptualize why it was important (Emerson et al., 1995; Higginbottom et al., 2013).

Ethical considerations

The study was registered and approved by the Danish Data Protection Agency, journal no. 2015-41-3682. All participants provided written informed consent. None of the participants withdrew during the study (NNF, 2003).

Data analysis

The transcribed field notes and interviews were analyzed according to inductive content analysis methodology (Elo et al., 2014; Graneheim, Lindgren, & Lundman, 2017; Graneheim & Lundman, 2004; Krippendorff, 2013). The analysis was conducted in four steps. First, the

transcribed data were read and reread to achieve an overall understanding of the content.

Secondly, meaning units were identified using the following two research questions: “How do carers interact in support groups?” and “What are carers’ experiences with caring for a person with dementia who lives at home?”. Thirdly, the derived meaning units were analyzed, condensed and labelled with a code. The codes were assembled based on their content, summarized and classified into subcategories and eight categories. Fourthly, the content of the categories was generated into three themes describing carer participation in support groups when caring for a person with dementia who lives at home (Table 1). The analysis was conducted by the primary author and continuously discussed with the research group. The analytic process continued until no further insights were found (Schreier, 2012) and the consistency of the coding process was ensured.

Rigour

The primary author achieved trustworthiness using a self-conscious and reflective approach throughout the data collection and analysis, with a precise description of the method and findings to ensure dependability of the collected data (Higginbottom et al., 2013). Knowledge gained from participant observations and semi-structured interviews was combined via a constant cyclic process to attain an in-depth exploration and understanding of the study aims (Cruz & Higginbottom, 2013). All authors read the transcripts independently. The authors discussed and agreed on the result of each step of the data analysis through scheduled sessions. This process ensures the credibility and validity of the abstraction process and findings.

FINDINGS

Three themes were identified: emotional well-being due to peer and family support, emotional sense of togetherness despite hardships and emotional and ethical considerations in caregiving.

Emotional well-being due to peer and family support

This theme embraces the strength carers gained as group participants, thus reflecting the positivity of peer interaction and how interaction helped carers to keep up their spirits as a family team.

The carers engaged with each other as soon as they arrived at the meetings. They greeted each other enthusiastically, smiled a lot and seemed happy to be there, as this field observations describes:

“Carer Si4 seemed genuinely happy to be at the meeting. She had a big smile on her face while she ensured that there were enough coffee cups for everybody for the coffee break later. She quietly stated that it was good to see the other carers again. That statement seemed to make the other carers profoundly happy (Field note Si, 1219-1221).”

The positive peer interaction allowed the carers to voice care problems, thereby making those problems real and providing new perspectives on solutions to challenges in caregiver situations. As one female carer said:

“Well, when you talk about your problems adjusting to the caregiver situations, for an outsider it must sound like you are complaining non-stop. That is not the case. It is just a case of allowing yourself to say it aloud, so you can get it out of your system. It is about being given the time and place to say it aloud. Moreover, someone will listen

and suddenly, you can hear it yourself. You get yourself sorted, so that everything is easier to handle. The problems are there. They are not fictive or something we made up in our imaginations” (carer Si6).

Participating in the support group exceeded the carer expectations because it was perceived as a time of growth and as a positive influence. Furthermore, the positive interactions in a group atmosphere lifted the carers’ moods. A female carer said:

“I have learned so much by attending this group. We who are part of this group are strong. So strong” (carer Si12).

Moreover, the carers were aware that everybody should have the opportunity to talk and often consciously remained silent to let others express themselves. This awareness led to an increase in the level of openness among the whole group.

Two pairs of siblings as well as a father and his daughter felt an intense joy and well-being about being together in a group, as it helped them to keep their spirits up as a team. The group gave them the opportunity to discuss the impact of dementia on the family structure.

As one sister expressed:

“It is so nice to be in this group with my sister. We didn’t discover our mother’s dementia at the same time. I thought for a long time that something was wrong, but my sister couldn’t see it” (carer Sy7).

Discussing the changes in their lives reduced the risk of potential conflicts with their changing roles in the family and in relation to the care receiver. These discussions enabled the families to plan caregiving together and to discuss issues that might otherwise have been avoided, leading to increased self-esteem and stronger cohesiveness between family members. A daughter said:

“I am so happy to be in this group with my father. I think its super. My father gained a lot of strength from participating, but at the same time is it a big surprise that he uses this group so much. That he talks as much as he does. I did not see that coming” (carer Sy5).

Emotional sense of togetherness despite hardships

This theme concerns the unity between the carer and the care receiver and reflects the alliance of love, mutual powerlessness, intimacy, the erosion of self and planning. How married carers talked about their love and affection toward each other as reciprocity and love was a vital part of the emotional sense of togetherness. The care receiver was losing the ability to reciprocate these feelings, which made the carer focus on friendship instead. The carers' humility and lack of demands were significant. The carer felt a need to highlight positive caring experiences as a way of remembering life with the care receiver, who at times was unable to recognize the carer. One wife expressed:

“We have been married for 52 years. That is not something you throw away like a crate of bad apples. As long as I can do it, I will. I will take care of him as long as I am able to do so” (carer Si2).

Such an alliance of togetherness enabled the carer to cope with the stressors of caregiving situations. The faithfulness and kindness toward the care receivers gave the carers strength, motivation and increased self-esteem as well as feelings of personal growth, confidence, satisfaction and purpose, as they had to learn new skills to cope with the daily challenges of caring. One wife said:

“He is still such a sweet man. Presently, I have to do all the work in the house and garden by myself, but it gives me a lot of strength to learn new skills. I have

discovered that I am able to do those things and it is not a problem. It feels great”
(carer, Si10).

The carers tried to maintain a hopeful outlook on being able to stay together with the care receivers in their own homes for as long as possible. Planning for the future required carers to consider planning a future apart from the care receiver as the illness progressed. The carers viewed placement in a nursing home as both a last resort and a potential way out.

Despite their love for the care receiver, the deterioration of the receiver also led carers to experience embarrassment, frustration, stress and potential abuse, as reflected in the following observation:

“Carer Sy6 was red in the face, seemed upset and on the verge of tears. The carer mumbled that he found it increasingly hard to handle his wife's frustration and anger during visits with friends and family. She reacted by pinching his ear until it hurt. He put his hand up to his right ear while he told the group that he felt so embarrassed that his friends and family should witness this kind of scolding. The carer next to Sy6 padded his hand (field note Sy, 686-690).”

Losing face in public can lead to feelings of hardship, anger and mutual powerlessness. It took self-control not to escalate the situations and such self-control could not always be mobilized. A wife said:

“I see how he sometimes feels powerless. He yells and scolds me. I get a lot of verbal abuse and I just have to take it. Last week I couldn't. I just couldn't. I shouted back. I used a lot of ugly words, a lot of swearwords. There was nothing I could do. I just had to let it all out” (carer SY3).

Emotional and ethical considerations in caregiving

This theme revealed the carers' emotionally supportive efforts in the context of the ethics of respecting the person with dementia. The findings showed that carers had to face daily ethical issues and were adamant that the care receiver be treated with respect, dignity and ethical considerations. The general lack of respect toward the care receiver from society was a source of great concern and anger for the carers, as the care receiver often became agitated and sad when faced with these attitudes. As a daughter said,

"It is so easy to lose respect for human beings who act a bit different and maybe are less bright than the rest of us. I have discovered how my mother's friends talk to her and I think it is so embarrassing and degrading" (carer Sy8).

The carers felt that the lack of respect was due to family and friends' lack of understanding of the illness, as the care receiver often looked healthy, but lacked social skills in social settings. This situation led to feelings of embarrassment and sorrow among the carers and to positive support for each other, as explained by female Si12 in the following observation:

"Carer Si12 seemed upset and looks around the table. She talked quietly about how it had become increasingly difficult to interact with friends, who could not understand or accept that her husband was ill because the illness was invisible. The carer next to her put an arm around her shoulder to comfort her. She explained how her husband had been respected among his peers, but now he said inappropriate things and laughed at the wrong time in social settings, which embarrassed her. The group nodded their head in agreement (field note Si, 1069-1074)."

The carer tried to protect the care receiver by expressing love and respecting the care receiver's choices in everyday life. As the illness progressed, the carers became very conscious about situations where they had to go against the care receivers' wishes when they

were deemed dangerous, impractical or unrealistic. The illness forced carers to take on the role of an authority figure in the relationship with parents or spouses. The carers talked about the shock they experienced when realizing that they had to take on responsibility for an adult family member.

At the same time, most carers kept their support group participation a secret to prevent hurting the care receivers' feelings. A daughter expressed:

“My mother doesn't know that I am participating in the group meetings. How am I supposed to say where I am when I know that the truth will make her really unhappy?” (carer Sy5).

DISCUSSION

The aim of the study was to explore and understand carers participation in support groups when caring for a person with dementia who lives at home. At present time we have not found any previous focused ethnographic study of carers support group participation in dementia. This approach helped to explore how carers live, experience and understand life as caregiver and identify perspectives of how carers shared positive and negative experiences can help reduce the negative consequences of providing care.

Our findings revealed that support group participation increased the level of openness between carers, which resulted in positive peer interaction and a group atmosphere that lifted the carers' moods. The groups became a refuge with a culture where trust was an integrated part of allowing everybody to speak their mind; the resulting feelings of well-being had a positive influence on carers' self-esteem. The present study shows that the increased self-esteem adds new perceptive insights on caring that enable carers to better cope with caregiving. According to Mason, Clare and Pistrang (2005), the emotional support of the

groups often corresponds with feelings of emotional well-being rather than with gaining knowledge of caregiving. Findings show that through the complex social peer interaction, the carers gained insight into caregiver situations from multiple perspectives, often resulting in positive attitudes toward their role as caregiver. Research show that discussing positive experiences helps sustain the carers' motivation to continue providing care as well as their sense of meaning in performing care (Cheng, Mak, Lau, Ng, & Lam, 2016; Yu et al., 2018). Our findings indicate that the carers expressed emotional well-being as an important result of the positive peer interactions and that support groups seemed to provide the opportunity to consciously focus on brighter aspects of the feeling of togetherness with the care receiver. Specifically, married carers found it extremely important to maintain the feeling of being a couple and to express and receive love and respect. This finding is consistent with studies showing that carers who focus on togetherness can maintain an active marriage despite the severe cognitive decline of the person with dementia (Davies, 2011; Merrick, Camic, & O'Shaughnessy, 2016; Molyneaux, Butchard, Simpson, & Murray, 2011). The current study demonstrated the need for carers, adult children and spouses to experience togetherness with the care receiver. This finding raises the question of whether the concept of togetherness has the same meaning for adult children caring for a parent with dementia as it does for spouses. The concept of togetherness in this study seemed to enable carers to cope with the stressors of caregiving and appeared to stimulate carer motivation and resilience to continue caring. The carers were also able to create positive family relationships that increased cohesiveness between family members. The participant's narratives showed that support group participation helped prevent conflicts in families. As the severity of the care situations was not apparent for all family members at the same time, the impact on the carers personal lives differed. The impact and the severity of the illness of the care receiver were discussed within the safety of the groups by carers who otherwise might not have spoken out within the

privacy of the family. Prior studies have shown that good relationships between siblings and family members can have a positive impact on the care receiver's well-being (La Fontaine & Oyebode, 2014; Livingston, Cooper, Woods, Milne, & Katona, 2008).

Previous findings showed that learning new skills made challenging caregiving manageable and problems solvable. A previous study found that carers derive meaning from caregiving when they achieve higher competences and motivations (Quinn, Clare, & Woods, 2012). Our findings suggest that achieving higher competences increased carer self-esteem and confidence in their caregiving abilities, enabling them to focus on the positive aspects of caring. Conversely, findings indicate that carers felt anger, powerlessness and difficulty mobilizing self-control when interacting with the care receiver. Our findings show that the carers needed to vent very dark thoughts about their life situation and the future. These negative experiences were recognized and added to by peers, thereby creating a sense of acceptance in the group that negative feelings were legitimate and nothing to be ashamed of. Venting negative experiences among peers is well known from previous research (Chu et al., 2011; Keyes et al., 2016; Shim et al., 2012). However, the present study also showed that carers experienced a lack of respect from surrounding society, which carers viewed as hurtful and harmful for the person with dementia. This finding concurs with the view of Signe and Elmståhl (2008) that maintaining ethical considerations and respect on behalf of the care receiver is a source of satisfaction for everybody involved. Our findings show that carers realized that successful caregiving depended on their ability to handle unpredictability and on their willingness to accept that the care receivers' choices were not always right. As the illness progressed, carers felt compelled to make decisions on behalf of the care receivers but taking on a role of authority was seemingly difficult. This finding resonates with the work of Chu et al. (2011), who found that being forced to make decisions on behalf of a person with dementia led to feelings of stress, crisis, anger, powerlessness and difficult caregiver

situations, as the carer and care receiver did not always see eye to eye. Accepting the shift of power in the relationship was a subject that the carers needed to discuss in-depth, as it came as a shock for most of them. This discussion seemed to ease the carers into handling the potential negative caring experiences of assuming authority over a person with dementia. Our findings showed that due to the perceived vulnerability of the care receiver, the secrecy of support group participation was viewed as protection. Group participation was viewed not only as a way out of social isolation for the carer but also as a potential source of embarrassment and resentment for the care receiver as well as a source of conflict between the carer and the receiver. Secrecy was a constant source of anxiety and nervousness for the carer, who risked being discovered participating in an activity where the aim was to speak freely about the negative and positive caring experiences of living with a person with dementia.

Limitations

The primary author was conscious about a possible Hawthorne effect (O'Reilly, 2009; Oswald, Sherratt, & Smith, 2014). The effect was overcome by building trusting relationships so the carers felt unthreatened by the primary author's presence at the group meetings. Additionally, by spending time with the primary author, it was less likely that the carers would modify their behavior when they knew they were being watched or studied, maintaining constant reflexivity during data collection (O'Reilly, 2009). Therefore, the qualitative findings in this study may be transferable and applicable to other contexts that involve complex social interaction and cultural context events in support groups for carers of people with other diseases and without a dementia coordinator as facilitator.

CONCLUSION

Our findings suggest that complex social peer interaction in the support groups, where the carer shared coexisting positive and negative caring experiences, can have a positive impact on their motivation to continue caring. Support group participation increased carer self-esteem and feelings of togetherness, raised awareness of maintaining the care receiver's dignity through ethical considerations, prevented conflicts in families and encouraged a shift in focus from negative to positive experiences. These outcomes resulted in improved carer well-being and, by association, the well-being of the care receiver. Healthcare professionals could improve carers' well-being by focusing on positive caring experiences and creating a positive atmosphere in support groups to help maintain their positive attitudes over time.

Our findings show that carers who keep their group participation a secret face a potential conflict with the care receiver. Future research could consider whether potential conflicts due to secrecy might be prevented by giving care receivers the option to participate in the support groups.

Conflict of interest statement

None declared

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Table 1. Example of the analysis process from participant statements to generation of the theme

Meaning unit	Code	Subcategory	Category	Theme
<i>“I have learned so much by attending this group. We who are part of this group are strong. So strong” (carer Si12).</i>	strong	supportive growth	Positive peer interaction	Emotional well-being due to peer and family support